Skin-related quality of life in children and adolescents with congenital melanocytic nevi - analysis of self- and parent reports

Neuhaus, Kathrin ; Landolt, Markus A ; Theiler, Martin ; Schiestl, Clemens ; Masnari, Ornella

Abstract: BACKGROUND: Congenital melanocytic nevi (CMN) may affect patient quality of life (QoL) due to medical complications (development of malignant melanoma or involvement of the central nervous system), skin-related discomfort or psychosocial sequelae. OBJECTIVES: To analyze skin-related QoL in children and adolescents with CMN and to identify predictors of low QoL. METHODS: Worldwide recruitment of participants through patient support groups. Data collection through a web-based survey. QoL was assessed using the Children's Dermatology Life Quality Index[I] (CDLQI). Demographic and CMN-related characteristics were examined as possible predictors of impaired QoL. RESULTS: 135 proxy-reports for children affected by CMN aged between 4-18 years (M = 9.34y, SD = 4.16y) and 28 self-reports of adolescents aged 14 -18 years (M =16.3y, SD = 1.2y) were included. The mean CDLQI score was 4.00 (SD = 4.39) for proxy-reports and 6.89 (SD = 5.85) for self-reports. Most parents (76%) reported 'no' or a 'small' impact, 19% a 'moderate', and 5% a 'very large' or 'extremely large' impact on their child's QoL. In self-reports, 46% of the adolescents reported 'no' or a 'small impact', 43% a 'moderate', and 11% a 'very large' or 'extremely large' impact. Visible CMN location, malignant melanoma, and higher child's age were important predictors of QoL impairments. CONCLUSIONS: Most CMN have a modest effect on QoL. However, there is large variability with a significant proportion of adolescents experiencing a moderate to large impact on QoL in contrast to children. Healthcare professionals should be aware of the predictors of QoL in children with CMN.

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DR. KATHRIN NEUHAUS (Orcid ID : 0000-0003-2438-1779)
DR. MARTIN THEILER (Orcid ID : 0000-0001-7160-3958)

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Authors: K Neuhaus[a], MA Landolt[b,c], M Theiler[d], C Schiestl[a], O Masnari[b]

Institutions:

[a] Division of Plastic and Reconstructive Surgery, Department of Surgery, University Children's Hospital Zurich, Zurich, Switzerland

[b] Department of Psychosomatics and Psychiatry and Children's Research Center, University Children's Hospital Zurich, Zurich, Switzerland

[c] Division of Child and Adolescent Health Psychology, Department of Psychology, University of Zurich, Zurich, Switzerland

[d] Division of Pediatric Dermatology, Department of Surgery, University Children's Hospital Zurich, Zurich, Switzerland

Corresponding Author:

Kathrin Neuhaus, MD

Division of Plastic and Reconstructive Surgery, Department of Surgery

University Children's Hospital Zurich

Steinwiesstrasse 75, 8032 Zurich, Switzerland

Email: kathrin.neuhaus@kispi.uzh.ch, Phone:, +41 44 266 7111

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ABSTRACT

Background: Congenital melanocytic nevi (CMN) may affect patient quality of life (QoL) due to medical complications (development of malignant melanoma or involvement of the central nervous system), skin-related discomfort or psychosocial sequelae.

Objectives: To analyze skin-related QoL in children and adolescents with CMN and to identify predictors of low QoL.

Methods: Worldwide recruitment of participants through patient support groups. Data collection through a web-based survey. QoL was assessed using the Children's Dermatology Life Quality Index© (CDLQI). Demographic and CMN-related characteristics were examined as possible predictors of impaired QoL.

Results: 135 proxy-reports for children affected by CMN aged between 4-18 years (M = 9.34y, SD = 4.16y) and 28 self-reports of adolescents aged 14 -18 years (M =16.3y, SD = 1.2y) were included. The mean CDLQI score was 4.00 (SD = 4.39) for proxy-reports and 6.89 (SD = 5.85) for self-reports. Most parents (76%) reported 'no' or a 'small' impact, 19% a 'moderate', and 5% a 'very large' or 'extremely large' impact on their child's QoL. In self-reports, 46% of the adolescents reported 'no' or a 'small impact', 43% a 'moderate', and 11% a 'very large' or 'extremely large' impact. Visible CMN location, malignant melanoma, and higher child's age were important predictors of QoL impairments.

Conclusions: Most CMN have a modest effect on QoL. However, there is large variability with a significant proportion of adolescents experiencing a moderate to large impact on QoL in contrast to children. Healthcare professionals should be aware of the predictors of QoL in children with CMN.

MAIN TEXT

Introduction

Congenital melanocytic nevi (CMN) are common birth marks and represent benign proliferations of melanocytes. Their incidence ranges between 1 and 6% for small to medium-sized lesions and around 1 in 20 000 for large CMN, which measure greater than 20 cm in diameter in adulthood [1–3]. CMN are highly variable in terms of their size, pilosity, color, and surface texture. They can occur anywhere on the integument as a single entity or may be accompanied by multiple other lesions [3,4].

Most CMN are uncomplicated, however, pruritus and skin fragility may occur. There is also a known risk for the development of malignant melanoma (MM) or central nervous system (CNS) abnormalities, both of which can be life threatening. The incidence of MM in patients with CMN has been overestimated over decades [5]. Recent and more reliable data has shown the overall risk of MM to be as low as 0.7% and increasing up to 3.1% in large CMN [6,7]. The incidence of CNS involvement is inconsistent, however larger size, higher number of satellite lesions and multiple CMN are clearly associated with increased occurrence [6,8].

CMN may affect quality of life (QoL) due to skin-related discomfort (e.g., pain, pruritus, or skin fragility), neurological symptoms associated with CNS involvement, or due to complex treatment, such as sequential surgical procedures. Moreover, CMN may lead to psychosocial difficulties and impaired QoL due to their atypical appearance [8–10].

The impact of skin diseases on various dimensions of QoL has been well described [10]. Most reports have investigated common skin conditions such as acne, vitiligo and atopic eczema, but there is a paucity of data on QoL for individuals with CMN [10–12]. One study has found lower health-related QoL in children and adolescents with CMN compared to population norms, but generic instruments were used which may lack sufficient sensitivity for dermatology-specific impairments [13]. To date there is only one study assessing dermatology-specific QoL instruments

[14]. This study found an overall low impact on skin-related QoL, but did not analyze potential predictors of QoL.

The aims of this study are to assess patient self- and proxy-reported skin-related QoL in a large sample of children and adolescents with CMN and to identify predictors of QoL impairments, including general patient as well as CMN specific characteristics.

Patients and Methods

Study Population:

The data presented herein is a subset of a large patient recruitment effort assessing QoL and psychological adjustment in children and adolescents with CMN. Participants were recruited worldwide with the help of CMN patient advocacy and support groups. Furthermore, in Switzerland, participants were recruited from the interdisciplinary CMN clinic at the University Children's Hospital Zurich by means of distributing recruitment brochures to eligible families. All data points were collected through a web-based survey.

Patient eligibility criteria were a) self-identification of adolescents with a CMN respectively of parents that their child has been diagnosed with a CMN, b) age of the child ≤ 18 years for proxy reports and 14 to 18 years for self-reports, and c) adequate knowledge of the English language to complete the survey. Partial or complete removal of the CMN was not considered to be a criterion for exclusion. Informed consent was obtained electronically prior to starting the survey. No personally identifying information was obtained. Proxy- and self-reports were collected separately allowing for the possibility that adolescents only, parents only or both participated. The Cantonal Ethics Committee from Zurich, Switzerland, gave declaration of no objection for this study.

Measures:

Skin-related QoL: Proxy- and self-reported skin-related QoL was assessed using the CDLQI, which is the most widely used instrument to measure the impact of a skin disease on QoL in children and adolescents [15]. The measure consists of 10 items relating to the week prior (see Table 1). Each item is scored on a 4-point Likert scale, ranging from 'not at all' (0) to 'very much' (3). A total score is calculated as the sum of all items (Range: 0-30). Higher scores indicate greater QoL impairment. Internal consistency in this study was good for both, proxy- (Cronbach's α= .83) and self-reports (α= .87). As suggested by Waters et al., the following severity bands were used: 0–1 'no effect'; 2–6 'small effect'; 7–12 'moderate effect'; 13–18 'very large effect'; 19–30 'extremely large effect' on QoL[16].

*Surgery***:** Respondents were asked whether the CMN had been managed surgically. Possible answers were: no surgery, partial removal, or full removal. For multivariate analyses, a dichotomous variable (full removal yes/no) was used.

Location and extent of the skin lesion: Respondents were presented a figure of a child, in which the body surface area was divided into 122 squares of the same size. They were asked to indicate how many squares were affected by the CMN or by a scar resulting from a nevus excision. The number of affected squares was assessed separately for the following body parts: face, scalp, neck, collar, arms/shoulders, hands, chest, abdomen/flank, back/buttocks, and legs/feet. A score for the body surface area (BSA) affected by the skin lesion was computed as sum of all affected squares (potential range 0-122). For multivariate analyses, dichotomous variables were used, indicating whether a specific body part was affected by the skin lesion or not.

Health status: Respondents were asked to indicate any chronic health condition as well as any of the following CMN-related health problems: malignant transformation of the nevus, neurocutanous melanocytosis, and neurological problems.

Skin-related symptoms: Intensity of the following symptoms over the past few weeks was rated on a 5-point Likert scale, ranging from 0 (no problem) to 4 (very severe): pain, pruritus, dryness, skin fragility, bleeding, and hypohidrosis.

Socioeconomic status (SES): SES was assessed using the MacArthur Scale of Subjective Social Status. Assessment of subjective ratings of familial placement in society was carried out as proposed by Goodman et al. [17]. Three social classes were defined as follows: lower SES (0-4), middle SES (5-7), and upper SES (8-10). For statistical analysis, the raw score (possible range 0-10) was used. Further demographic information included age, sex, and country of residence.

Statistical analyses:

SPSS software (Version 24, IBM Corporation, 2016) was used for data analysis. Two-sided tests were used for all analysis and a value of $p < .05$ was considered significant. Post hoc power analyses ($\alpha = .05$, two-tailed) were performed using the G*power software [18]. For proxy-reports our sample size (n=135) provided good power (>.92) to detect medium to large effect sizes ($\rho = 0.3$, $f2 \geq 0.15$) in bivariate correlations and regression analyses, but not enough power to detect small effect sizes ($\rho = 0.1$, $f2 \leq 0.02$). For self-reports (n=28), power was acceptable (.79) to detect large effects ($\rho = 0.5$) in bivariate correlations, but not enough to detect small or medium effect sizes. Notably, the sample size of self-reports was too small to perform multiple regression analyses. Bivariate Pearson correlations were conducted with all possible predictor variables and the following outcome variables: self- and proxy-reported (1) CDLQI total score, (2) CDLQI item 2: 'Feeling embarrassed, self-conscious, upset or sad because of the skin', and (3) CDLQI item 3: 'Calling names, teasing, bullying, asking questions, or avoiding'. Subsequently, for proxy-reports, predictors with $p < .05$ were analyzed using multivariate regression analyses. Independent variables were entered simultaneously into the regression model.

Results

Sample Characteristics:

A total of 136 parent proxy reports were received. A single report was excluded from further analysis because parents reported a severe health condition which had a greater impact on their child's life than the CMN, leading to a final sample of 135 proxy reports. With respect to self-reports, two cases were excluded for the same reason as above, resulting in a total sample of 28 self-reports. Table 2 shows detailed sample characteristics for proxy and self-reports. Proxy reports were mainly provided by the mother (88%), followed by the father (7%), by both parents (4%), or by a grandmother (2%).

Table 3 shows the frequencies of self- and proxy reported skin-related symptoms. The highest incidence were found for dryness in proxy reports and pruritus in self-reports.

Skin-related QoL:

Analysis of CDLQI demonstrated that all aspects of QoL were affected to some degree by the skin lesion in both, proxy as well as self-reports (Table 1). The highest ratings in proxy reports were found for 'itchy/painful skin' (Q1) and 'being called names/teasing' (Q8), whereas in self-reports the greatest impact was reported for 'feeling embarrassed/self-conscious' (Q2) and 'clothing decisions' (Q4). Mean CDLQI total score was 4.00 (SD = 4.39) in parent-reports and 6.89 (SD = 5.85) in self-reports.

The range of scores demonstrated large variability, with 19% of parents and 43% of adolescents reporting a 'moderate effect' and 5% of parents and 11% of adolescents reporting a 'very large' or 'extremely large' effect on QoL, respectively (Table 4).

Predictors of skin-related QoL:

Bivariate Correlations between potential predictor variables and QoL outcomes are shown in Table 5. Table 6 summarizes statistics for three regression models predicting proxy-reported QoL outcomes. The selected predictors accounted for 12% of the variance in the CDLQI total score, 15% for 'feeling embarrassed, self-conscious, upset, or sad because of the skin', and 14%

for experiencing 'name calling, teasing, bullying, questions, or avoiding'. Impairment of total skin-related QoL was significantly predicted by occurrence of MM and CMN located on hands. Feeling self-conscious/upset was predicted by increasing age of a child, occurrence of melanoma, and CMN located on the hands or face. Involvement of the hands or face were also significant predictors for experiencing stigmatization, such as teasing, name calling, bullying, questioning or avoiding.

Discussion

The first aim of this study was to assess self- and proxy-reported skin-related QoL in children and adolescents affected by CMN. Proxy as well as self-reports showed that CMN affect all aspects of QoL as measured by the CDLQI. The average overall impact of CMN on QoL was found to be rather small, especially in parent-reports. The variance in the total CDLQI score, however, was large, with 24% of parents and 54% of adolescents reporting a 'moderate' to 'extremely large' effect on QoL. A direct comparison of proxy- and self-reports is not possible in this study due to significant differences in the sample population, including age range and CMN characteristics.

Many skin diseases have been shown to have an impact on QoL that is comparable to other severe medical conditions, such as cancer, heart disease, and diabetes [10,11,19]. Our results are in line with those of Wramp et al. [14] who published the only other study on skin-related QoL in individuals with CMN . They analyzed a cohort of 55 individuals with CMN aged 4 years to adulthood and also found large variability of scores and similar overall impact on QoL, with about 20% moderate to severe impact. Their study participants, however, were recruited through a German CMN patient support group resulting in a small sample that is limited to a specific geographical region unlike our study population, which is considerably larger and encompasses patients from all over the world.

Olsen et al. performed a meta-analysis of studies using the CDLQI questionnaire to assess the impact of a skin disease on QoL in children [10]. Most of the 67 publications included in the study focused on common dermatological conditions, such as acne, atopic eczema, or vitiligo. The mean score across all studies showed a 'small effect' on QoL similar to our results. When comparing different skin conditions, the authors found a 'small' impact on QoL for acne, vascular anomalies, vitiligo and warts, with mean scores similar to that in our CMN sample. Mean scores for atopic eczema and psoriasis, on the other hand, were considerably higher indicating a 'moderate' impact on QoL. These higher scores can be reconciled when considering that the aforementioned conditions show a fluctuating course with unpredictable flare-ups, causing significant itch, sleep disturbance, and a varying degree of aesthetic impairment. This stands in contrast with conditions such as CMN, which usually cause little or no physical symptoms and generally carry a stable clinical course. In our study, the largest effect on QoL reported in self-reports was for clothing decisions and 'feeling embarrassed, self-conscious, upset or sad because of the skin', suggesting that CMN may cause an emotional rather than a functional impairment of QoL in adolescents. This finding is in line with the results of our previous study assessing generic health-related QoL in children and adolescents with CMN [13].

Addressing our second study goal, this study is the first to identify predictors of impaired dermatology-specific QoL in children and adolescents with CMN, namely occurrence of MM and visible CMN location (hands and face). Of note, other variables, such as gender, complete removal of the CMN or extent of the skin lesion did not predict QoL outcomes. Feeling self-conscious/upset was predicted by higher child age, reported occurrence of MM, and CMN located on the hands or face. Involvement of the hands or face was also a significant predictor for experiencing stigmatization. These results are in line with previous findings [9,19,20] suggesting that lesions on visible body parts, are associated with experiences of stigmatization, including

intrusive questions, teasing, and bullying. Such experiences might lead to feelings of self-consciousness and impairments of psychosocial functioning [9]. Increasing feelings of self-consciousness and embarrassment with higher age can be explained, when considering that infants may be too young to be aware of the social implications of their condition. Difficulties may arise in early school years when children increasingly engage in social comparisons with peers and in adolescence when appearance and peer acceptance are of utmost importance. Accordingly, previous studies found higher QoL impairments in adolescents compared to younger children [12,14].

Although we identified visibility as a predictor of impaired QoL, many previous publications found no direct effect of size and visibility of a skin lesion on generic health related QoL or psychological adjustment [21]. There are, however, reports suggesting an indirect effect through stigmatization [13]. The identification of a direct effect in our study may be explained by the utilization of a dermatology-specific instrument for measuring QoL. The CDLQI includes specific questions addressing clothing decision, staring, going out/swimming, and hobbies, which are likely influenced by the visibility of the skin lesion.

The strengths of the presented study are the large sample size, the inclusions of children and adolescents with a broad spectrum of CMN sizes and irrespective of their previous medical treatment, the assessment of proxy- as well as self-reports, the use of a well-known dermatology-specific QoL instrument, and the analysis of possible predictors of skin-related QoL. However, some limitations merit note. First, the cross-sectional design prevents any conclusions about causal relations. Second, the recruitment of participants through patient advocacy and support groups might have led to a selection bias, as it could be that individuals experiencing more difficulties are more likely to be involved in such organizations. Further, the overall sample size for self-reports was too small to allow multivariate analysis. Proxy reports included a large age range (4-18 years), but the sample size was too small for age-dependent

subgroup analysis. Such analyses would be of value as it is likely that challenges related to a skin condition vary throughout different developmental periods, such as preschoolers and adolescents. Finally it must be noted that we included children ages 4 to 18 years, which extends beyond the initial CDLQI design for children ages 4 to 16 years [15].

Our results have significant clinical implications. About 11% of adolescents reported a 'very large' to 'extremely large effect' on their QoL. This highlights the importance of screening for QoL impairment in the clinical assessment of patients with CMN. Identified predictors of QoL help to recognize patients at highest risk for difficulties. Such patients may benefit from referrals to psychosocial specialists. Knowledge and awareness of potential QoL impairment in children and adolescents with CMN can improve patient guidance and management. This is especially important since CMN are no longer treated with surgical excision as the standard treatment to reduce a previously overestimated risk of malignancy. Instead, families' interest to have surgery are rooted in aesthetic and psychosocial considerations in most cases. Psychological assessments should be integrated in clinical management as they can impact proposed medical treatment strategies. Furthermore, patient advocacy and support groups might be an important source of information and social support for patients and families.

Future research should include longitudinal data, analyze developmental effects, and address psychosocial consequences of treatment decisions (e.g. surgical removal of a CMN) as well as satisfaction with treatment. Since identified predictors in this study only account for little variance in QoL outcomes, the search for other predictors should be continued.

In conclusion, overlooking the largest sample size of children and adolescents with CMN assessed so far, this study provides evidence that CMN impact on skin-related QoL in children. Although the overall impairment appears to be small, the range is wide with a considerable

number of adolescents experiencing a large effect. Screening for QoL impairment should therefore be included in the evaluation of children with CMN and be incorporated into therapeutic decision making. Further research, ideally longitudinal, is needed to gain more insights into the mechanisms underlying QoL impairments and psychosocial adjustment in individuals with CMN.

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Tables

Table 1: Impact of the skin lesion on different aspects of quality of life according to proxy- and self-reports.

CDLQI questions	Proxy reports (N = 135)					Self-reports (N = 28)				
	Not at all (0)	Only a little (1)	Quite a lot (2)	Very much (3)	M (SD)	Not at all (0)	Only a little (1)	Quite a lot (2)	Very much (3)	M (SD)
Q1. Itchy, "scratchy", sore or painful skin	51.1	37.8	9.6	1.5	0.61 (0.72)	44.4	37.0	14.8	3.7	0.78 (0.85)
Q2. Embarrassed, self-conscious, upset or sad because of skin	60.7	29.6	5.2	4.4	0.53 (0.79)	17.9	57.1	14.3	10.7	1.18 (0.86)
Q3. Friendships	76.3	20.0	2.2	1.5	0.29 (0.58)	71.4	25.0	3.6	0	0.32 (0.56)
Q4. Clothing decisions	63.7	21.5	11.1	3.7	0.55 (0.84)	33.3	33.3	18.5	14.8	1.48 (1.06)
Q5. Going out, playing, or hobbies	75.6	17.8	4.4	2.2	0.33 (0.67)	57.1	28.6	7.1	7.1	0.64 (0.91)
Q6. Swimming or other sports	80.7	11.1	4.4	3.7	0.31 (0.73)	50.0	21.4	7.1	21.4	1.00 (1.22)
Q7. Schoolwork/Holiday in past week	84.4	15.6	0	0	0.16 (0.36)	71.4	10.7	14.3	3.6	0.52 (0.89)
Q8. Calling names, teasing, bullying, asking questions, or avoiding	59.3	30.4	4.4	5.9	0.57 (0.83)	50.0	35.7	10.7	3.6	0.68 (0.82)
Q9. Sleep	82.2	11.1	5.2	1.5	0.26 (0.62)	82.1	14.3	3.6	0	0.21 (0.50)
Q10. Effect of treatment on quality of life	70.4	23.0	4.4	2.2	0.39 (0.68)	60.7	28.6	10.7	0	0.50 (0.69)
CDLQI Total sum score					4.00 (4.39)					6.89 (5.85)

Note. Frequencies are reported in case percentages. CDLQI = Children`s Dermatology Quality of Life Index.

Table 2: Sample characteristics for self- and proxy reports.

Variable	Proxy-reports (N=135)	Self-reports (N = 28)
Sex		
Female	72 (53.3%)	25 (89.3%)
Male	63 (46.7%)	3 (10.7%)
Age, years		
Mean (SD)	9.34 (4.16)	16.3 (1.2)
Range	4-18	14-18
Socioeconomic status, M (SD)	6.81 (1.46)	6.4 (4.9)
Lower (0-4)	7 (5.2%)	3 (10.7%)
Middle (5-7)	72 (60.7%)	18 (64.3%)
Upper (8-10)	46 (34.1%)	7 (25.0%)
Country of residence		
Europe (total)		
Great Britain (UK, Ireland)	20 (14.8%)	4 (14.3%)
Germany and Switzerland	23 (17.0%)	3 (10.7%)
Southern Europe	5 (3.6%)	5 (17.8%)
Belgium and The Netherlands	7 (5.2%)	2 (7.1%)
Scandinavia	6 (4.5%)	0
Other European countries	5 (3.7%)	1 (3.6%)
United States and Canada	55 (40.8%)	7 (25%)
South America	1 (0.7%)	1 (3.6%)
Australia, New Zealand	9 (6.7%)	2 (7.1%)
Africa	0	1 (3.6%)
Asia	4 (3.0%)	1 (3.6%)
Not provided	n.a.	1 (3.6%)
Previous surgical excision of CMN		
None	49 (36.3%)	9 (32.1%)
Partial removal of CMN	72 (53.3%)	16 (57.1%)
Full removal of CMN	14 (10.4%)	3 (10.7%)
Location of the skin lesion		
Face	49 (36.6%)	9 (32.1%)
Scalp	45 (33.6%)	8 (28.6%)
Neck	23 (17.1%)	7 (25.0%)
Collar	19 (14.2%)	3 (10.7%)
Arms/shoulders	43 (32.1%)	8 (28.6%)

Hands	22 (16.4%)	4 (14.3%)
Chest	37 (27.6%)	7 (25.0%)
Abdomen	53 (39.6%)	11 (39.3%)
Back	87 (64.9%)	20 (71.4%)
Legs/feet	64 (47.8%)	18 (64.3%)
Genitals	32 (23.9%)	6 (21.4%)
BSA score		
Mean, SD	13.63 (16.92)	16.11 (24.23)
Range	1-112	1-106
CMN associated medical conditions		
Central nervous system involvement	14 (10.6%)	n.a.
Neurological problems	16 (11.9%)	n.a.
Malignant melanoma	4 (3.0%)	n.a.
Other chronic health conditions		
Asthma	5 (3.6%)	5 (18.0%)
Allergies	14 (10.3%)	6 (20.0%)
Eczema	3 (2.1%)	1 (3.6%)

Note. CMN = Congenital melanocytic nevus. BSA = body surface area

Table 3: Frequency of proxy- and self-reported skin-related symptoms.

	Proxy-reports (N = 133-135)					Self-reports (N = 27-28)				
Variable	No Problem (0)	Moderate (1)	Severe (2)	Very severe (3)	M (SD)	No Problem (0)	Moderate (1)	Severe (2)	Very severe (3)	M (SD)
Pain	85.8	13.4	0.7	0	0.15 (0.38)	74.1	25.9	0	0	0.26 (0.45)
Itchiness	46.7	49.6	3.0	0.7	0.58 (0.59)	46.4	42.9	10.7	0	0.64 (0.68)
Dryness	37.8	51.9	8.1	2.2	0.75 (0.70)	53.6	39.3	7.1	0	0.54 (0.64)
Skin fragility	50.4	42.1	5.3	1.5	0.57 (0.67)	57.1	35.7	7.1	0	0.57 (0.84)
Bleeding	85.7	12.0	1.5	0.8	0.17 (0.47)	78.6	21.4	0	0	0.21 (0.42)
Decreased sweating	55.6	33.1	7.5	3.8	0.59 (0.79)	64.3	35.7	0	0	0.36 (0.49)

Note. Frequencies are reported in valid case percentages

Table 4: Impact of congenital melanocytic nevi on skin-related quality of life (CDLQI total score).

	Proxy-reports for children ages 4-18 years (N =135)		Self-reports of adolescents ages 14-18 (N= 28)	
	n	%	n	%
No effect (0-1)	54	40.0%	7	25.0%
Small effect (2-6)	49	36.3%	6	21.4%
Moderate effect (7-12)	25	18.5%	12	42.9%
Very large effect (13-18)	6	4.4%	1	3.6%
Extremely large effect (19-30)	1	0.7%	2	7.1%

Note. CDLQI = Children`s Dermatology Quality of Life Index

Table 5: Bivariate correlations between predictor variables and quality of life outcomes.

	Proxy-reports (n = 134-135)						Self-Reports (n = 27-28)					
	CDLQI total sum score		Self-consciousness/ Feeling upset		Teasing/ Questions		CDLQI total sum score		Self-consciousness/ Feeling upset		Teasing/ Questions	
Variable	r	p	r	p	r	p	r	p	r	p	r	p
Age of child	.12	.17	.20	.02	.07	.41	.50	<.01	.32	.09	.32	.10
Male sex of child	-.07	.46	-.05	.57	-.07	.42	-.13	.50	-.21	.29	-.15	.45
Socioeconomic status	-.20	.02	-.09	.29	-.11	.20	-.49	<.01	-.44	.02	-.23	.24
Melanoma	-.25	<.01	-.22	.01	-.04	.65		n.a.		n.a.		n.a.
NCM	-.13	.15	-.02	.81	-.22	.01		n.a.		n.a.		n.a.
Neurological problems	-.07	.40	.05	.61	-.14	.12		n.a.		n.a.		n.a.
Complete surgical removal of CMN	-.05	.56	-.05	.60	.00	.99	-.19	.32	-.45	.07	-.01	.98
Location of the skin lesion												
Face	.15	.09	.19	.03	.31	<.001	.12	.55	.31	.11	.18	.36
Scalp	.15	.09	.10	.27	.20	.02	-.09	.67	-.02	.93	-.21	.89
Neck	.07	.45	.07	.45	.08	.35	-.05	.80	-.10	.61	-.04	.83
Collar	.01	.93	.02	.81	.04	.64	-.09	.66	-.20	.32	-.14	.50
Arms/shoulders	.10	.27	.06	.50	.16	.06	.39	<.05	.27	.17	.10	.62
Hands	.27	<.01	.24	<.01	.37	<.001	.70	<.001	.54	<.01	.33	.09
Chest	.02	.82	-.04	.65	.16	.07	-.05	.80	-.10	.61	-.04	.83
Abdomen	.14	.10	.01	.91	.11	.21	.30	.13	.26	.18	.14	.48
Back	.08	.35	-.02	.87	.06	.51	.21	.29	.13	.50	-.06	.78
Legs/feet	.05	.59	.05	.57	.11	.23	.27	.16	.25	.21	-.02	.92
Genitals	.06	.52	-.00	.96	.02	.79	.64	<.001	.51	<.001	.44	.02
TBSA score	.11	.20	.08	.39	.16	.07	.73	<.001	.56	<.01	.36	.06

Note. CDLQI = Children`s Dermatology Quality of Life Index. NCM = neurocutanous melanocytosis. CMN= Congenital melanocytic nevus. TBSA = Total body surface affected by the CMN. n.a. = not available

Table 6: Summary of multiple regression analyses predicting proxy-reported skin-related quality of life outcomes.

	Model 1				Model 2:				Model 3:			
	CDLQI total score				Self-consciousness/ Feeling upset				Teasing / Questions			
Variable	B	SEB	β	p	B	SEB	β	p	B	SEB	β	p
Age of child	0.11	0.09	.10	.22	0.04	0.02	.20	.02	0.01	0.02	.04	.61
Socioeconomic status	-0.48	0.26	-.16	.06	-0.03	0.05	-.05	.52	-0.05	0.05	-.10	.24
Malignant melanoma	-6.35	2.45	-.22	.01	-1.33	0.44	-.25	<.01	0.47	0.43	.10	.28
Neurocutaneous melanocytosis	-1.16	1.30	-.08	.37	-0.05	0.23	-.02	.82	-0.18	0.23	-.07	.44
Face	1.17	0.77	.13	.13	0.31	0.14	.19	.03	0.40	0.14	.25	<.01
Scalp	-0.15	0.84	-.02	.86	-0.06	0.15	-.04	.70	0.04	0.15	.02	.82
Hands	2.80	1.07	.23	.01	0.53	0.19	.24	<.01	0.54	0.19	.25	<.01

Note. Model 1: R = .41 (n = 130, p < .01), R^2 = .17, R^2 adj. = .12. Model 2: R = .44 (n = 130, p < .001), R^2 = .20, R^2 adj. = .15. Model 3: R = .43 (n = 130, p < .001), R^2 = .18, R^2 adj. = .14. CDLQI = Children`s Dermatology Quality of Life Index.